



April 19, 2021

Representative Clay Yarborough, Chair  
Representative Michael A. Caruso, Vice Chair  
Representative Dotie Joseph, Ranking Member  
House HHS Finance & Facilities Subcommittee  
214 House Office Building  
402 South Monroe Street  
Tallahassee, FL 32399

Dear Chair Yarborough, Vice Chair Caruso, and Members of the Finance & Facilities Subcommittee,

On behalf of the 1,650 people with cystic fibrosis (CF) in Florida, we write to express our support for HB 1111, which would require insurers to apply third-party assistance to out-of-pocket maximums and other patient cost-sharing requirements. While copay assistance is a short-sighted fix for systemic issues that face our health care system, solutions to address affordability and sustainability cannot come at the expense of patients' health and financial wellbeing.

Cystic fibrosis is a life-threatening genetic disease that affects more than 30,000 children and adults in the United States. CF causes the body to produce thick, sticky mucus that clogs the lungs and digestive system, which can lead to life-threatening infections. Cystic fibrosis is both serious and progressive; lung damage caused by infection is irreversible and can have a lasting impact on length and quality of life. As a complex, multi-system condition, CF requires targeted, specialized treatment and medications. While advances in CF care are helping people live longer, healthier lives, we also know that the cost of care is a barrier to access for many people with the disease.

Accumulator programs—which prevent third-party payments from counting towards deductibles and out-of-pocket limits—can have a direct, negative effect on treatment adherence for people with CF and lead to adverse health outcomes. According to a survey conducted by George Washington University of over 1,800 people living with CF and their families, nearly half reported delaying or forgoing care—including skipping medication doses, taking less medicine than prescribed, delaying filling a prescription, or skipping a treatment altogether—due to cost concerns. Because CF is a progressive disease, patients who delay or forgo treatment face increased risk of lung exacerbations, irreversible lung damage, and costly hospitalizations.

Accumulator programs also place additional financial strain on people with CF who are already struggling to afford their care. More than 70 percent of respondents in the aforementioned survey said paying for health care has caused financial problems such as being contacted by a collection agency, filing for bankruptcy, experiencing difficulty paying for basic living expenses like rent and utilities, or taking a second job to make ends meet. And while three quarters of people received some form of financial assistance in 2019 to pay for their health care, nearly half still reported problems paying for at least one CF medication or service in that same year.

We understand the challenge insurers face in managing the rising cost of drugs, and that copay assistance programs mask bigger cost and affordability issues in the health care system. However, cost

containment strategies that place a further burden on patients are unacceptable. The CF Foundation supports efforts that allow third-party assistance to count toward deductibles and out-of-pocket limits, particularly for patients with chronic conditions like CF. The Foundation urges health insurers and pharmaceutical manufacturers to come to the table to discuss long-term solutions that do not place disproportionate financial pressure on patient and families.

While we understand that there may not be sufficient time remaining this legislative session to pass HB 1111, we look forward to working with you to advance this critical policy in the coming months and next session. Your support of this effort will help ensure continued access to quality, specialty care for Floridians with CF. The Cystic Fibrosis Foundation appreciates your attention to this important issue.

Sincerely,

A handwritten signature in black ink, appearing to read 'Mary B. Dwight', with a stylized flourish at the end.

Mary B. Dwight  
Chief Policy & Advocacy Officer  
Senior Vice President, Policy & Advocacy  
Cystic Fibrosis Foundation

Cc: Representative Demi Busatta Cabrera, Sponsor  
Representative Vance Arthur Aloupis, Jr., Co-Sponsor  
Representative Anna V. Eskamani, Co-Sponsor  
Representative Rick Roth, Co-Sponsor